

Talking to your child about clinical trials

If you're reading this, you may have started thinking about clinical trials.

Perhaps your child has shown an interest in clinical trials, asked you how their treatments are made, or questioned something from a science lesson at school. Or perhaps they haven't shown an interest themselves, but you'd like them to take part in a trial in the future.

Even to adults, clinical trials can seem daunting, and explaining them to younger children can feel like a challenge. Here, we'll explain how to talk to your child about clinical trials and how to use the Junior Agents comic to start these initial conversations. You can also take a look at some tips from parents of children with CF as well as a CF psychologist.

JUNIOR Agents

Reading the comic together

The Junior Agents comic is designed to introduce primary-aged children with CF to clinical trials. It explains what clinical trials are, what taking part in one might involve and how getting involved in one could help children with CF like them. The idea of Junior Agents was developed to encourage children to see clinical trials as something interesting and exciting, and to show them that their condition gives them special skills that could help them and others.

You may want to read the comic with your child to allow you to answer any questions and to find out what they already know. You might end up having conversations in the future about specific trials, but this comic is designed to help you have those first conversations that will help to get your child used to the idea of taking part in a trial.

The comic also includes Junior Agent badges on the back page for your child to cut out, fill in and give to a member of their CF team. It doesn't commit them to a trial, but it's a way to show they'd be happy to talk about a clinical trial 'mission' when one comes up that's right for them.



Tips from other parents

Here are some tips from parents whose children have taken part in CF clinical trials. Every parent-child relationship is unique, and you'll know best how to speak to your child. Remember to use age-appropriate language - visit cysticfibrosis.org.uk/trialsglossary to help you explain complicated terms.

- "Make sure they know that taking part in a trial is their choice, and they can leave at any time."
- "Explain that a trial might not benefit them, but could help other people with cystic fibrosis."
- "Tell them that trials are a way to help those who look after them and that everyone (scientists, doctors, fundraisers) is working together to make CF medicine better. Explain any feedback and progress throughout the trial."
- "Talk to your child on their own at first and then include the rest of the family. Siblings might need to be prepared for their brother or sister to attend more appointments."
- "Be prepared - talking about clinical trials might lead to your child asking about other tricky aspects of cystic fibrosis."
- "Even if your child is young, it's still important to talk to them about clinical trials so you have their consent to be involved."

Take a look at five treatments used by people with CF today, thanks to clinical trials: bit.ly/35mvoQv

Advice from a CF psychologist

"It's natural to feel daunted when talking to your child about cystic fibrosis. As a parent, you might be caught between wanting to protect your child and wanting to help them develop the knowledge and skills they'll need for the future. If you are considering involving your child in a clinical trial, it's an opportunity to help them to understand more about CF and how medicines are made, and to allow them to be part of the decision."

- Dr Jess Brown, Principal Clinical Psychologist, York Teaching Hospital

- **Setting the scene:** Pick a time when you won't be distracted (avoid bedtimes and mealtimes!) If you find it hard to talk about CF, pick a time that feels manageable for you too.
- **Starting the conversation:** Children take cues from their parents, so try to keep your tone light and curious. Start by finding out what they know about how medicines are made, use language they'll understand and don't try to cover everything in one go. You may end up talking about trials over a few days.
- **Answering questions:** Listen to the whole question and try to answer it without adding lots more information. If you don't know the answer, great! That helps children to feel okay about not knowing things, and you can ask your child's CF team the question together. It can be useful to have a book to write questions in.
- **Checking understanding:** Open questions like "What do you think about being a Junior Agent?" can encourage talking and help you spot any confusion. Asking children to explain things or joining them in learning is a good way to normalise the topic and reassure them, eg "Making new medicines is new to me too, maybe you can help me by explaining how you think it works?"

Remember, your role here is to be a parent, not an expert in clinical trials! By having these conversations, you can help your child learn more about CF, feel okay about asking questions and think about what part they could play in medical developments.

For more information on clinical trials, visit cysticfibrosis.org.uk/clinicaltrials